PRESS RELEASE

Contacts:

Henrik Boysen
Executive Director, HAEi
P: +45 31 591 591
E: h.boysen@haei.org

Anthony J. Castaldo
President, HAEi
P: +1 202 297 3409
E: a.j.castaldo@haei.org

Patients with Hereditary Angioedema (a potential life-threatening swelling disorder) call for improved access to available treatments

Nancy, France – 17 January 2011 – "Patients with hereditary angioedema continue suffering from painful, debilitating, and potentially life threatening swelling attacks despite the availability of effective treatment options," according to a report issued by Hereditary Angioedema International (HAEi)—the global umbrella non-profit organization that represents patients with hereditary angioedema (HAE). The report, *'State of Management of HAE in Europe - Facing up to Hereditary Angioedema,'* reveals misdiagnosis, delays in diagnosis, and unsatisfactory treatment standards across Europe and Israel. Based on the report's findings, HAEi has issued a Call to Action that includes specific steps that are required to ensure that HAE patients have access to suitable treatment and therefore can lead a normal life. The report's conclusions were based on data gathered during a recent HAEi-sponsored patient advocacy forum and the results of a survey conducted in 11 European countries and Israel.

"HAE patients experience recurrent attacks (swellings) of different parts of the body, which in some cases, can be life threatening. There are treatments for HAE approved by EMA across EU but we have found extreme variations in availability and access. Patients in some countries have no access to available treatments, while patients in other countries have the opportunity to choose between a variety of therapies. We are calling for action that will reduce the burden of HAE and raise patients' quality of life by providing access to the full range of available treatment options," says Henrik Boysen, Executive Director of HAEi.

While HAE cannot yet be cured, intelligent use of available medication can help to prevent the onset of symptoms and effectively manage attacks. However, the report revealed that HAE is all too often under-recognized, under-diagnosed, and under-treated.

"HAE patients are not making unreasonable demands. Patients want to control their symptoms so they feel safe and are able fulfill their life's potential at school, work and in relationships. HAEi believes that every patient should have an individualized treatment plan that includes home treatment as a viable option. Our Call to Action formalizes what we consider basic patient rights," says Anthony J. Castaldo, President of HAEi.

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About HAE

HAE is a rare and potentially life-threatening C1 inhibitor deficiency disorder with symptoms of severe, painful and recurring attacks of edema (swelling) in airways, internal organs, face, hands and feet. The condition affects between 1:10,000 and 1:50,000 people worldwide, many of who suffer for years, often receiving unnecessary medical procedures and surgery, before learning an accurate diagnosis. Most attacks occur spontaneously with no apparent reason although factors ranging from anxiety to illness and trauma have been cited as triggers.

Swelling of the throat and airways can result in death by suffocation and must be treated as an emergency with prompt medical attention. Almost all patients experience abdominal attacks that involve severe and excruciating pain, vomiting and diarrhea. Swelling in the face, hands feet and other body parts is extremely painful, disfiguring and debilitating. An untreated attack lasts between 24 and 72 hours and can go on for over a week.

About HAEi

HAEi – International Patient Organization for C1 Inhibitor Deficiencies – is a global non-profit organization dedicated to raising awareness of C1 inhibitor deficiencies around the world. Our purpose is to join efforts and experience of the global HAE community to achieve optimal standards of care and treatment for HAE patients.

Read more about HAE and HAEi on our website: www.haei.org